

# Animating Disability Differently: Mobilizing a Heterotopian Imagination

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## Abstract

This article takes up Goodley's challenge to explore the ways in which poststructuralist research methodologies open up new ways of thinking about encounters with disability. Working with the materiality of their own encounters with disability and the conceptual possibilities opened up in poststructuralist and new materialist thought, the six authors deconstruct the ability/disability binary through animating disability differently. They draw on memories generated in a collective biography workshop to explore the ways in which concepts, such as heterotopia, can be put to work to mobilize a humanity-in-common that is both multiple and open to differentiation, that is, to continuously becoming different.

## Keywords

heterotopia, animation, differentiation, disability, collective biography, normativity

Few of us fancy being pathological so “most of us” try to make ourselves normal, which in turn affects what is normal.

—Hacking (1990, p. 2)

In any binary, there is a dominant term that works as a signifier of what will count as normal and desirable, and a subordinate term that is read as ab-normal and undesirable. Members of any subordinate category are subjected to normative pressure to become more like those who are read as normal. At the same time, those who are deemed to be “normal” take themselves to be so *in relation*, and as *other* to members of subordinate categories (such as female, Black, gay, homeless, or disabled). Deconstruction of binaries begins by reversing the hierarchy and celebrating the subordinate category. Fritsch (2015) takes up that challenge in her article “Desiring Disability Differently.” The concept of heterotopia is central to her deconstructive work.

Inspired by Fritsch's deconstructive move and by Chen's (2012) use of the concept of animacy, the six authors decided to explore these concepts further through a collective biography workshop in which we set out to think disability differently. We focused on opening up, in our collective biography work, a heterotopian imagination with which to animate disability differently. We wanted to dislodge it from the abled/disabled binary, not by making the disabled more “normal,” or by stretching the category of abled to include the disabled, but by animating disability differently.

*So what do we mean here by heterotopia?* Originally, the term heterotopia (Greek for *heteros* “another” and *topos*

“place”) was used in the medical field to refer to a particular tissue that developed in an unusual place, and which was merely dislocated, not necessarily diseased or dangerous (Johnson, 2006). Inspired by the medical meaning of the term, Foucault developed this concept, differentiating it from utopia—that ideal society that we have all inevitably failed to accomplish. Heterotopic places he defined as “other spaces,” spaces that were “out of place” and “unfamiliar,” and as spaces in which the elements do not add up to a logical whole (Saldanha, 2008). Heterotopic sites are thus counter-sites that “have the curious property of being connected to all the other emplacements” (Foucault, 1967/1998, p. 178).<sup>1</sup>

Foucault (1967/1998) nominated six characteristics of a heterotopic place: (a) heterotopic places are everywhere; (b) in the course of history each heterotopia can operate, exist, and function in different ways; (c) a heterotopic place is made up of incompatible emplacements; (d) a heterotopic place involves a break within traditional (linear) time and this discontinuity opens up heterochronies; (e) a heterotopic place assumes a system of opening and closing that isolates it and make it penetrable at the same time; and finally (f) a

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heterotopic place has a function in relation to the remaining places. Heterotopic places, and by extension heterotopic events, practices, and relationships have something that makes them an obligatory point of passage (Hetherington, 1997), which leads us not to the question of what a heterotopia is, but what it can do and what it can open up.<sup>2</sup> The concept of heterotopia is thus a vehicle that can open up disability as multiple, as always emergent, and as intra-corporeal. It effects an intervention in the normative social order and the psychic life of power (Butler, 1997).

*And what do we mean by animation?* The methodology we have used here, of collective biography, could itself be described as an animating methodology. The participants work with language in such a way that lives might be told/lived differently through disentangling themselves from the repetitive clichés, moral judgments, and familiar explanations that more usually shape the telling of personal memories. Participants tell their stories to each other, not as autobiographical “I” stories, but as stories that seek to open up, in the collective space of listening, an insight into the collective life we are all part of. This shift in linguistic strategies *matters*, that is, it materially affects the storytellers and listeners; it affects what can be told and what can be heard. It affects what is animated in the telling/hearing/writing of memories.

Chen (2012) says of language itself, it

is as much alive as it is dead, and it is certainly material. For humans and others, spoken and signed speech can involve the tongue, vocal tract, breath, lips, hands, eyes, and shoulders. It is a corporeal, sensual, embodied act. It is, by definition, animated. (p. 53)

Storytelling/writing/reading in collective biography workshops is material in Chen’s sense, and its strategies are specifically designed to bring language to life. At the same time, collective biography works with concepts that further animate their stories, while the stories work to animate the concepts—to make them live.

Deconstruction also involves looking at the ways language works to hold binaries in place. Understanding the way individuals are positioned in relation to categories, and the onto-epistemological effects of that emplacement is vital in deconstructive work. Being categorized within a subordinate category means that you are *marked* by that category (Davies, 1993). Those in the dominant or ascendant half of any binary are not so marked, and can assume, without paying the matter any attention, that they are superior to those categorized as being in the subordinate category. They are simply normally and naturally human. Being marked as disabled leaves a trace on the skin, a disablist “*epidermal schema*” (Fanon, 1993, p. 112; see also McRuer, 2002).<sup>3</sup> Those schemas, lived in the skin, are “relics of societal discourses, emanating from expert and lay knowledge, reproduced in institutions of family,

school, prison, disability service and hospital” (Goodley, 2011, p. 103). One is made a member of what Schneider (2015) calls the *precariat*. The *precariat*, in effect, functions as the outside other to “the autonomous, rational subject that can smoothly move his body in accordance with what is considered acceptable and appropriate within the social sphere” (Fritsch, 2015, p. 48). Yet no one wants to be pathologized, as Hacking (1990) said, and what will count as normal is open to change. In this article, we set out to use language differently to animate precarious lives, as lives that count, and as lives with epidermal schemas full of that life, and as lives integral to the humanity that we are all part of.

*Last, but not least, what do we mean by differentiation and normalization?* Deleuze and Guattari (1987) identify two major lines of force that are at play in any social encounter. One is a normalizing or territorializing force, dependent on repeated citations, that works to keep everything the same. The other is a creative evolutionary or de-territorializing force that opens up the new, the not-yet-known, and the emergent possibility of becoming different, of differentiation.<sup>4</sup> These two lines of force are constantly at play, affecting each other and depending on each other. The second is mobile rather than static, and it is multiple rather than singular.

Binary categories work to trap the subordinated other in the first line of force and to offer much more of the creative, experimental, mobile elements of the second force to those in the dominant unmarked group. Yet Deleuze suggests “that we are all part of the same Being, and at the same time, that we are multiple and emergent” (Wyatt, Gale, Gannon, & Davies, 2011, p. 2). He suggests that each being in his or her specificity is of the same matter and mattering as others, affecting and being affected by others, singly and collectively differentiating themselves, becoming other than they were before. Always and at the same time, each being is at risk of being caught up in individualizing themselves, getting stuck in repeated citational chains that close down movement and close down openness to difference and to the other (Davies, 2014). We suggest as well that being categorized as disabled, as *other* to the normative subject, can stop the fluid movements of differentiation. Those who are placed in the subordinated category, “disabled,” may find themselves limited in the intra-actions through which their life might be lived, the repeated ascriptions of subordinate category membership effectively shutting down the possibilities of differentiating.<sup>5</sup>

Normativity is a force that runs counter to differentiation.<sup>6</sup> Habituated ideas and ideals of humanness draw everyone, irrespective of abilities or disabilities, into discursive practices that are not simply a superficial gloss on what it is to be human, but rather, constitutive of it. In those habituated spaces, individuals strive to perfect themselves through normative ideals that are not of their own making but are laid down through normative discourses and material practices

(Butler, 1997; De Schauwer & Davies, 2015). This individual endeavor is so taken-for-granted that it is read as a natural process, intrinsic to individuals. Furthermore, because the accomplishment of oneself as rightfully occupying an ascendant category is read as natural, the forms of normativity at work on bodies are made invisible: “[P]ower works on bodies so as to produce and naturalise a self-governing subject who subscribes to neoliberal individualism and economization and ableist configurations of disability” (Fritsch, 2015, p. 47). This naturalization and invisibilizing of power, we suggest, fuels what Kafer (2013) calls the “ableist failure of imagination” (p. 4). It seems not possible to imagine: “Maybe there is an overwhelming sense of gloom or maybe the consequences of imagining differently would result in being ridiculed, pathologised or at best, ignored” (Campbell, 2009, p. 20). Furthermore, when it is imagined to be a *natural* process, those who are perceived to be *not* appropriately striving to realize or embody normative ideals of autonomy, flexibility, beauty, and self-determination are read as monstrous and alien—as not recognizable as properly human (Shildrick, 2002).

What then are the possibilities of developing a *multiplicity* of readings of disability (Goodley & Runswick-Cole, 2012) that enable us to animate disability differently and to unsettle what will count as “normal” (Hacking, 1990)? The concept of heterotopia and animation can be put to work to transcend binary thinking, and heterotopic imagination can save us from being trapped in a story line of intractable and subordinated otherness. Instead of functioning as the constitutive outside to what will count as normal and as human, we ask how might those who are disabled be recognized as being entangled, *as anyone is*, in both the forces of *normalization* and of *differentiation*?

One of the difficulties in deconstructive work is that those in subordinated categories have found ways to survive in their subordinated position. They do not necessarily want to lose their category membership and whatever benefits they have found that go with it. Political work has been done to gain compensation for their lesser status. Benefits of that work include the allocation of resources to assist those categorized in the enterprise of becoming more “normal” and thus potentially productive. At the same time, categorization can lead to the withholding of freedoms that are the prerogative of those constituted as normal—freedom to be *multiple*, to *differentiate* oneself in an emergent process of becoming other than what one was before, to be creative and experimental, and to even shift the boundaries of what will count as normal. Once categorized, the “disabled” are deprived of those freedoms. Instead, they are deemed to be in need of (medical, psychological, social, educational) remediation or treatment, designed to bring them closer to the norm—that being constituted as the only thing anyone could ever want to be (De Schauwer, Van de Putte, Blockmans, & Davies, 2016).

## Collective Biography: Method

Collective biography is a postqualitative research strategy using a diffractive methodology developed by Davies and Gannon and their colleagues (2006, 2009, 2013), where a “diffractive analysis can be understood as a wave-like motion that takes into account that thinking, seeing and knowing are never done in isolation but are always affected by different forces coming together” (Lenz Taguchi & Palmer, 2013, p. 676).

Collective biography works with the collaborative telling of stories in which a theoretical concept can be put to the fore from the outset. It is not focused on whether an individual’s stories or memories are “reliable” or not, rather it is interested in creating knowledge about the discursive and intra-active practices through which people and events emerge in all their multiplicity.<sup>7</sup>

Collective biography works with poststructural theory and new materialism and against the grain of phenomenology’s liberal-humanist subject.<sup>8</sup> It has emerged over the last two decades as an intra-active and emergent set of concepts and practices that de-individualize those doing the research, re-constituting them in and as an entangled, emergent multiplicity (Davies & Gannon, 2013).

The participants in collective biographies are not positioned as entities that pre-exist the research but as beings “mutually implicated” in their “differential becoming” (Barad, 2008, p. 147). They are emergent in the space of the workshop—a space-time-mattering that does not separate out past, present, and future. The ideas and concepts, the stories that are told, the embodied telling, hearing, writing, and reading of those stories, enables the workshop participants, together, to form an entangled phenomenon of collective, embodied, biographical becoming in the space-time-mattering of the workshop.

Prior to the collective biography workshop, in which the six authors of this article participated, and out of which this article emerged, the authors gathered weekly for two months for reading sessions that included writings of, among others, Barad (2007), Bennett (2010), Butler (2001), and Fritsch (2015). Through our readings and discussions, heterotopic imagining emerged as the focus of the work we would do in our workshop.

In October 2015, all six authors lived together for three days in a cozy house in the Flemish countryside to explore heterotopic imaginings through our remembered stories and through which we might experiment with animating disability differently. In those three days, we told stories of conflict, confusion, categorization, and reconciliation. Sometimes tears were shed while telling our own stories and while listening to the stories of others. As each story was told and listened to, we wondered out loud, opening ourselves to the bodily affect and effect of each story, seeking to know what it is to be this person, or these people in

this story in that space, and at that time.<sup>9</sup> After that telling and wondering, we each wrote our stories, avoiding clichés and explanations and moral judgments, and we sought words that could evoke the specific embodiment of the remembered moments. Furthermore, in an innovative extension of the methodology, we explored the material specificity of our stories through painting and through making clay models of the characters and of the material objects in our stories.<sup>10</sup> Using those clay models and paintings, we made short animated films of each story. The moments in our stories were thus multiply animated through the words we uttered, through the sound of our voices as we spoke and listened to each other, and through the sensual engagement with paint and clay and the visual surprise of the films themselves. We then read our stories out loud to each other, and showed our animated films, all the while engaging in emergent listening,<sup>11</sup> intra-acting both with each story and storyteller. The cycle of telling, writing, making films, reading out loud and showing our films, listening again for feedback on the way our stories affected the listeners, then re-writing, meant that the intra-active presence of the group shaped what it was possible to say-feel-write-animate-read-write. This storying process is thus intra-corporeal; bodies, and their animation of selves and other, affect each other, and are affected (Chen, 2012).

In the emergent listening, the questioning, and in the subsequent re-writing, the incompatible, heterotopic elements of each story found their way onto the page. Not all of the elements could be encapsulated in one telling, or even two. The three stories that we ultimately chose to work with in this article reflect many overlaid spaces and not just one perfect space or moment in time. Through re-telling, questioning, re-writing, and animating each story, mono-chromatic and linear stories transformed themselves into stories that captured more of the heterotopic elements of the remembered event and reflected as well the multiplicity of those others entangled in the stories. The mobilization of heterotopic imagination worked to focus our attention on the emergent emplacements, the multiplicity of beings, and the multiple entangled forces (both ontological and epistemological) that were at play in the remembered moments of being.

## Happy Birthday!

The first remembered moment takes us to the birthday of Olivia.<sup>12</sup> In this story, Olivia was 20 years old and rented a room in the city of Ghent where she was studying some distance from home. Olivia had been told she lived on the autism spectrum disorder (ASD). She preferred to refuse that category although she understood and saw that there was something different when she compared herself with her two younger sisters. At the time of Olivia's 20th birthday, only one younger sister and her mother knew about her having been diagnosed and thus categorized as other to normal.

### Olivia's story

Last class of the day, I hope to see my mother this evening. I run upstairs with quick pace. When I'm almost at the top I spot my little wooden desk, standing in the hallway. I stop, stare confused at my desk and start running again, but faster this time. Anger enters my body immediately. I grasp my phone and type my mother's number while I give the creaky old door of my room a hard push. Before the phone has any chance to connect, I close it down. Panic takes over the anger when I see that a new big desk is standing in the middle of my room, at the very same spot where the old one used to stand. I see colorful drawings and collages with names and birthday wishes hanging on the walls, and hundreds of brightly colored flags. I hear girlish yelling and gurgling. I run toward the walls and tear off as many drawing as I can and smash them on the ground. I hear a lot of footsteps, I feel hands and arms around me, I hear more girlish yelling and I squeeze my eyes. I furiously try to get rid of all the hands and arms around me, I cry, I stamp, I squeeze my eyes even more and I'm out of breath.

When I open my eyes, the too excited girlish yelling has disappeared. I'm alone in my room. My old desk is still in the hallway and the drawings—some of them are torn—are spread all over the place. My face feels wet. Slowly I take the drawings in my right hand and with my left one I try to hang them back on the wall. I am feeling heavy. I am tired. Once back on the wall the drawings look like drooping and withered flowers. I'm jealous of all the nice colors, jealous of all the pleasure you can see in the drawings. I feel guilty. I tremendously hope I'll see my mum this evening.

At the moment of her 20th birthday, Olivia had believed she was getting settled—away from home—where she did not have to be “the big sister.” Away from home, she had finally found some strategies to live. When her younger sisters entered her “safe,” private room, she felt confronted by her failure as the big sister at home—confronted by the things she could not do. Those confrontations made her feel that everything she had fought for had been pointless. She would never be able to manage it all, to live “normally” like her two younger sisters.

When she thought about it later, drawing on the concept of heterotopia, the birthday surprise involved shifting the centerpiece of her room's order, the little old desk, out into the hallway. The desk, in this sense, was heterotopic—a *dislocated tissue* in the life of herself/her room. Whereas the desk had signified her smartness, her abilities, offering comfort and security, it now signified that which was to be excluded and abandoned. It was out of place like Olivia, odd, not like others, not good enough. There was danger in being singled out and excluded. Furthermore, her noisy younger sisters, who were integral to her life at home, had become dislocated tissue in her room as they shattered its peaceful order with their ecstatic encircling of their big sister, and with their joyful paintings and flags on the walls, and the gift of the large desk. For Olivia, in that moment,



the non-superposable places of home-family and room-successful student clashed in an unbearable way. Her sense of autonomy, embedded in the order of the room as it was, was shattered.

The moment of surprise was made up of different incompatible, overlapping, intersecting planes, objects, and persons. The room, the drawings, the old-new desk, the surprise, each person in their multiplicity offered some different way into the story. The room was, in the first instance, a safe place for Olivia, a place where she was not constantly confronted with the unpredictability and rush of family life and home. She had made, here, her own territory with all her books, her interests, her routines. Here she was the girl with possibilities, with nice grades, with friends. Here she became the big sister admired by her little sisters, who already dreamed about having the life she had. No other space was so perfect in Olivia's eyes although she was sometimes sad about the distance that excluded her from her family. In this manifestation of itself, the room was inextricably connected with the dominant order (Topinka, 2010), in which autonomy is linked to successful university study, the appropriate separation of self from family, and the development of independent friendships. The orderliness of the room and its materiality—the books, the desk, the computer—were intimately linked with Olivia's successful accomplishment of a sense of herself as living a normal life. But the normative order *also required* Olivia to manage the movement from one place to another, and from one set of relations to another. If she was to be counted as normal, and not as a member of a subordinate category, she could not depend on one form of orderliness. She could not lock herself down in a limited set of repeated citations. She must be open to the unexpected—to differentiation and thus to creative evolution. The first line of force that Deleuze and Guattari outline, of normalizing/territorializing, a force that is at play on everyone, and that we all depend on to feel safe in a predictable world, necessarily intra-acts with the second force, the riskier, differentiating line of force.

After her mother and the girls were gone, there was a pause, a threshold, a liminal space, *and* a crossing over into embracing the drooping flowers her sisters had painted for her and a longing to see her mother (De Schauwer & Davies, 2015). Olivia emerges as the one attached to her small desk *and* confronted by its abjection in the hallway *and* the one who cannot cope with the disturbance to her order *and* the one who longs for the capacity to cope with surprise and the bright flags and flowers that signal celebration. She enters into a heterotopic space of overlapping multiplicities.

In the workshop, in the spirit of a heterotopian exploration of multiplicity and of intra-corporeality, Olivia re-told the story from the viewpoint of her mother.

#### The Mother's story

Unbelievable, it's almost 20 years since I gave birth to Olivia. Every year I remind her of the fact that it is a miracle we survived. But to celebrate this day with her is not always that easy. The two youngest have been making drawings for their big sister the whole week. We will surprise her with a new big desk. She will be happy with it and we will buy the same desk for her at home and maybe then she will be more able to study at home with us . . . Maybe.

"Okay girls, ready? We have 30 minutes. Nora, can you take the small desk outside—put it in the hallway, yes, that's okay. And you Emma, can you help me to put all her stuff back. Do you remember how her computer was standing?"

"Mom, can we hide and surprise her when she enters her room?" Nora asks.

"Well . . . I think so, but be a little gentle, don't overwhelm her . . . OK?"

"Ssshht, I think I hear her . . . Yes, she is here . . ."

Do I need to go first and prepare her, tell her we decorated the room as a surprise? No, no, she will handle it, she will be happy to see us, . . . no?

"SURPRIIIIIISSE!"

"Happy Birthday little one! Come here, so I can hug you." "What do you think of the new desk? That's the one you wanted, no?" "Are we going for a drink?"

. . .

"Nora and Emma, calm down!"

"Nora, sshht!"

Okay, this is not going well . . . I need to handle it . . . quick, but what do I need to do? Didn't she want to have her sisters with her?

"Listen, Olivia, I will come back . . . do you hear me? It's alright, you can take the pictures down, yes, no problem, it will be fine. Look, I will bring the girls home first. Okay? Stay here and I'll come back. Okay?"

"Come on girls, back in the car. Let Olivia go."

Maybe this was not a great idea . . .

In this heterotopic, multiple reading of the birthday, it is possible to read Olivia as emergent and multiple—not locked into her categorization, and at the same time always

connected to those other beings and those other things and places through which she comes to exist. Olivia's room was heterotopic. To begin with, it was a place out of place, different from all the rest of the places, even while it was also connected to the other places such as the university. Then, it became heterotopic in another sense, of containing incompatible elements. Those incompatible elements momentarily obliterated Olivia's story that she was autonomous and competent, and mobilized instead another story of her own embodied self, being out of place and unacceptably different. In the first sense, the heterotopic elements hold everything in the room in place; in the second sense, they generate a burst of energy, of rage. The storm of emotion, and Olivia's longing to be joyful like her sisters, lies on the brink of an intra-corporeal transformation where life might be imagined and lived differently. This writing takes Olivia once more to that threshold and catches her up in that process of differentiation, of becoming, always incomplete.

## The Tattoo and the Wind: Loss and Resistance

Our second story works with the idea that a person with a disability, like any human subject, is in constant motion, always emergent and transforming the barriers of his or her labels. The story involves "*the mutual constitution of entangled agencies*" (Barad, 2007, p. 33) on a warm afternoon among a gentle breeze, a girl, her uncle, a barbecue, and an idea. The girl and her uncle have, together, experienced massive and multiple losses. In a car accident, nearly 25 years ago, the uncle lost his mother, brother, and nephew, while the girl lost her grandmother, father, and brother, as well as her ability to walk. The story has several overlapping non-superposable emplacements: the current place of the barbecue where the breeze blows the napkins on the table and gently lifts and whirls the falling leaves, and where she is in conflict with her beloved uncle; the place of the accident in which they both lost their family members; and the idea of a tattoo of the wind on the shoulder of the girl in the wheelchair.

The sun is setting, making me feel warm, peaceful, thankful for this beautiful moment of family time. A cool summer breeze moves the napkins.

"I think I'd like a tattoo on my shoulder."

My uncle turns away from the barbecue. "Why would you want a tattoo?"

I hear disapproval in his surprised voice. I had not expected that one coming.

"Well, I met this girl three years ago who had a tattoo on her left hip to draw the attention away from the scar she had on the

other side and I quite like the idea. I don't like the scar on my back, and I believe a tattoo might do the trick."

My uncle looks down, directing his gaze to a point beyond me.

"Are you sure you want to do that?"

"I think so . . . I quite like the idea of an image of the wind on my shoulder, also as a way to remember everyone who has passed away."

"But you'll be mutilating your body," my uncle interrupts.

I want to say "I feel their presence most when nature is at work, when the sun is making the tip of my nose glow, when the wind is catching leaves in their fall, lifting those beautiful creatures whirling around."

The napkins lie still. The gentle breeze has paused, bracing itself.

Instead, I say "I'm not. The accident has mutilated my body. This time I am the one who is deciding that something is happening to my body, and for once, it is going to be something good and beautiful."

"You are not mutilated. And that's different. That just happened."

I stop talking. The crispy bacon on the grill calls for my uncle's attention.

The girl and her uncle, both have their own grief, sorrow, memories locked in their bodies. They have an intimate history of remembering their beloved ones, the uncle sharing his memories, and the girl taking them in, in every detail, because she has no memories of her own of her grandmother, dad, and brother. She was too young to be able to remember them.

For the girl, the tattoo of the wind will breathe life into all the beloved ones who have passed away. The tattoo will give her something tangible that can remind her that they once existed in this world and that they can continue to inspire her. The tattoo has creative potential, her grief of lost love and traumatic loss will be carried, and will continue to be carried, acknowledged, inscribed mutely on her shoulder, like a beautiful jewel, that you can show in summer. It will create a new epidermal schema of simultaneous beauty, inspiration, and loss. She is grieved by her uncle's inability to move with her, to feel inspired by her idea.

For the girl, the tattoo is a powerful means of asserting her freedom from the category of "disabled"—from being defined as unworthy, inadequate, and dependent (Fritsch, 2015) and it signifies the control she still has over her own body. It represents her ability to be more than "disabled"

and to escape from the *epidermal schemas* of dependence, lack of control, lack of attractiveness, and lack of self-love. The girl has found with the tattoo a graphic, embodied way to resist and take control of these dominant notions of unattractiveness/dependence/. . . by means of creating something beautiful for herself on her own skin.

The place of the barbecue and the place where the tattoo might be worked on her body are non-superposable in the uncle's (utopian) thinking in which there can only be one truth. Whereas the girl had brought them together into the same space, bringing as well the lost members of the family into this space where the breeze brushed against her shoulder, her uncle needed to keep them separate.

Her uncle's words affect her, pushing her up against her non-membership of the normalized, unmarked category of the able-bodied subject. The forms of experimentation and rebellion that the normative subject is entitled to are not freedoms she can explore as far as her beloved uncle is concerned. His automatic rejection, which normative subjects might take in their rebellious stride, confronts her, and it deflates her sense of pleasure in her image of a tattoo of the wind. It becomes, instead of something beautiful, an unacceptable mutilation of an already mutilated body. The uncle's and the girl's losses are connected, but their ways of dealing with their losses are (for now) incompatible—non-superposable.

The tattoo of the wind now on the girl's shoulder makes her happy and invokes the irresistible longing to jump around whenever she sees it in the mirror; she feels nervous if she has not reassured herself of its presence. At the same time, she feels deeply saddened by her uncle's opposition. The process of having the tattoo done, though, was not without pain; just as touching the saxophone that her father used to play, or seeing a picture of her brother who will never turn two, is not without pain. The intra-active space between the girl and her uncle mirrors and reflects the tensions that the forces of normalization produce. On one hand, in her uncle's resistance to the tattoo, there is the protective positioning of her *as* disabled, combined with the generalized (though now less common) belief that tattoos are dangerous insofar as they signal non-normativity. On the other hand, the girl's decision to get her tattoo opens up the possibility of thinking outside the definition of herself as disabled (Hetherington, 1997).

For some time, the uncle remains caught on a threshold where a normative and judgmental space-time-mattering holds him immobile, where the idea of the tattoo is heterotopic in the sense of being in the wrong place. He pauses, unable to make the leap into the other heterotopic space his niece has mobilized where incompatible elements can be brought together in an aesthetic resolution. The intra-corporeality of herself/her tattoo/her missing loved ones/and the wind on her shoulder enables her to exist differently, to no longer be identified primarily in terms of a subordinate category (De Schauwer & Davies, 2015).

## Captain Simon Leads the Battle

Our last story takes place on a hot sunny day when water was the only thing that could help everyone to cool down. It involves Simon, a 9-year-old boy with multiple disabilities, his two support workers,<sup>13</sup> Yannick and the storyteller, and their friend Petra. The pond is not open to the public although a lot of people ignore the prohibition sign, especially with the extreme heat in the summer. Yannick and Petra decide that they must make their way into the pond. To do so, they must climb over the fence, lift the wheelchair over, lift Simon over, carry the resources such as the auxiliary aid and several backpacks all the way to the water—it is quite an undertaking. Our story opens up a place-time-mattering in which Simon, a boy whom others would not think capable of swimming in a secluded pond, becomes a pirate and belongs to a playful group of friends in the water. Together with Yannick, he makes the pond unsafe as a pirate on the sea. Heterotopia, here, is a temporary passage disrupting the usual restrictions that come with the surveillance, control, and protection of children who are categorized as disabled. While his categorization is to the forefront, it is unthinkable that he might engage in such play.

Water is splashing. Simon is trying to hit Yannick but he misses and his hand splashes the water. Both of them have very white skin even though the sun has been out for a long time. Simon's body lies heavily on the "horse," which supports him, but his arms are dangerously circling around. Yannick points at Petra who is peacefully dozing off in the sun, her eyes closed, enjoying the sun on her skin, her hands at the side of her mattress gently moving in the water. Simon only needs two eyes looking at Petra to understand. "Attack!" he yells. The two boys are taking the "horse" in the direction of the mattress. "Here we come!" Simon enjoys the idea of what will happen and will do everything to speed up and reach Petra as soon as possible. Yannick is trying to keep him on the aid, while making all kinds of loud noises warning Petra that she will go in the water. With the front of the "horse," they hit the mattress and destabilize it. Simon grabs everything he can take hold of in order to pull Petra off. His spastic muscles make his movements big and his body is going in every direction. Yannick gives a push under another part of the mattress while using all of his strength to keep Simon on the horse. Petra is taken by surprise. "Oh la! What are you two doing?" The next moment, she goes in. While the two boys are enjoying their victory, she crawls back on her mattress and starts kicking with her feet. They have to withdraw for one moment and reorganize their troops. Simon is still shouting and his whole body wants to attack another time.

In that moment, in that space, Simon is not marked by what he is not able to do—his disabilities are not made to matter. He is part of the game in the pond. He is not on the margin of the game but at its center, in the middle of the pond. The hot sun, the cool water, the secluded pool, the auxiliary aid which has become a "horse," the mattress,

Petra, and Yannick all intra-act with Captain Simon in his becoming the gleeful and wicked pirate conspiring with Yannick, his mate, bringing laughter and joy to the whole group in the pond. The normative order, in which it would not even be imaginable to take Simon into the water, is no longer the dominant order. No longer is the focus on the failure of his body and the associated hardship for Simon and his carers. As Kafer (2013) says, “There is no accounting for how a disabled person’s response to impairment shifts over time or by context” (p. 4).

The game brings a glorious time-space-mattering of competency and escape. Together, intra-corporeally, the friends have become participants in an intra-active space in which Simon is the pirate, the gleeful warrior who, with his mate, succeeds in attacking Petra and getting her into the water. The sense of joy, of being in control, of being able to play are senses Simon not always has access to. He is *emergent* in that space of becoming pirate with Yannick.

The glorious space-time-mattering of pirates on the high seas co-exists with a non-superposable space-time-mattering of Simon the boy who is disabled. For the one to exist, attention has to be paid to the other. The place with all the fun and where he can enjoy becoming a pirate, necessitates attention to his difference; he needs a special aid in the water, he needs to be dried, three people need to take him out of the water, even with this warmth his lips turn blue after an hour. The intra-action of Simon-Yannick-water, is animated through “the horse”—the aid to support him in the water. A medical aid becomes a warrior’s tool assembled with the water, the two bodies, and the warriors’ sound. The horse exists in two non-superposable spaces at once; it both keeps him safe in the water and it creates a space for Simon to control what happens and to transcend his limitations through becoming pirate (McNamee, 2000).

This playful moment in the water of Simon-becoming-pirate may seem to have been too risky. But each line of flight, each de-territorializing move is risky, taking us out of the predictable safe space of the already known, repeated citations. Just as Olivia’s mother took a risk with the birthday surprise, and the girl with the tattoo risked losing her warm relationship with her uncle, so Simon takes a risk in becoming pirate.

To others, Simon’s adventure may seem not to have changed anything very much. They might see it as only a one-time happening in a certain place at a certain moment in time, but what happens *matters*. Simon’s life-as-pirate animates his life *as live*, as a life that counts, as a life with an epidermal schema full of that life, and as integral to the Being that his companions are all part of. The opening up of this space-time-mattering involves an opening up of imagination and it creates an intra-corporeal disruption of the mono-chromatic linear story line in which most of Simon’s life is entangled. In the pond, Simon is not determined only by his disabilities; there is heterochronic time and space for experiment, for risks and for pleasure and play.

## (In)conclusion

We have taken up Goodley’s (2013) challenge to use post-structuralist research methodologies to rethink disability. We have put the concepts of heterotopia and animacy to work in a deconstructive move on the ability/disability binary. Working beyond the positioning of those with disabilities as marked by their subordinate category and, as such, other-to-able-bodied/able-minded beings, we have sought to animate disability differently as simultaneously subjected to forces of normalization/territorialization and open to the emergence of the new.

By thinking in terms of disability as an emergent, intra-corporeal multiplicity, we open up the idea that a person with a disability, like any human subject, is in constant motion, always emergent, transformable, capable of resistance, and capable of transcending the constraints that accompany his or her embodiment and his or her categorization in a subordinate category. Disability, if we think of it in this way, is emergent within the interplay of several ways of being and thinking (De Schauwer & Davies, 2015): It is heterotopian.

Our heterotopic readings of our collective biography stories offer the practice of thinking differently *with* disability, not as other to the normatively embodied subject, but as multiple, emergent, and intra-corporeal (Fritsch, 2015). The methodology behind our story generation as well as our collective writing strategies was *diffractive*, that is, it opened itself up conceptually and in practice to multiple, competing, and overlaid lines of force. We unsettled the production of mono-chromatic, linear reflections of what might at first be taken to be the single truth of the matter in any particular encounter with disability.

We have sought to use the concepts of heterotopia and animacy to work with collective biography stories to move beyond the binary categorizations of people with a disability. We have suggested that the abled/disabled binary itself is intra-active and mobile. Normative discursive practices work to hold those diagnosed with a disability in a static place of otherness and it is this dynamic we have sought to disrupt. Although categorization is politically useful in generating necessary resources, such as a wheelchair, professional support workers, and an auxiliary aid that becomes a horse, it is also dangerous in its capacity to relegate those categorized to an intractable position of other-than-normal, and other-than-human—to being someone without the right of access to humanity with all its creative evolutionary potential. These two incompatible dynamics are non-superposable, and can co-exist, not in a utopian space, but in a heterotopic space, a space that is diffractive and mobile, where “thinking, seeing and knowing are never done in isolation but are always affected by different forces coming together [. . .]” (Lenz Taguchi & Palmer, 2013, p. 676).

The opening up of a new space-time-mattering is not a linear causal movement that seeks to change the whole



world into an (ever-receding) utopian dream. Thinking with heterotopia, we can see how the moments of animating disability differently open up a momentary resolution of the incommensurabilities of encounters with disability. Each heterotopian space-time-mattering is in relation to multiple other space-time-matterings that continue to affect any resolution in contradictory ways. At the same time, through animating disability differently, in all its emergent intra-corporeal multiplicity, the lived heterotopian space inevitably intra-acts with, and affects those other spaces. Animating disability differently in heterotopic moments of being has the power to affect normative space-time-mattering, we suggest, in as yet unforeseeable ways.

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### Notes

1. Foucault (1966) mentioned heterotopia for the first time in the preface of his book, *Les mots et les choses*, where it mainly refers to textual spaces. In the same year, he uses the concept during a radio broadcast about utopia (transcript was published in 2009 by Defert). Finally, Foucault published a text (*Des Espace Autres*) about heterotopia in 1967.
2. Different academic study fields elaborated on Foucault's concept of heterotopia: In sociology and cultural studies, for instance, the concept of heterotopia is not only interpreted as concrete geographical places or realities, but also as social, cultural, spiritual, and relational realities marked by incompatibility, discontinuity, and difference (Hetherington, 1997; Meininger, 2013).
3. The terms *ableism* and *disablism* are both used in the literature that we draw on in this article, where "disablism (is) the exclusion of people with impairments) and ableism (the system by which standards of human anatomy and capability are made as key indicators of human worth)" (Liddiard & Goodley, 2016, p. 152).
4. Differentiation refers to distinguishing multiple differences among people according to their category memberships, while differentiation refers to the ongoing emergence of difference, emphasizing continuous change.
5. We use Barad's (2007) term *intra-act*, rather than the more familiar term *interact*. "Interact," Barad argues, is a relation between two separate entities, while her neologism, *intra-act*, looks not just at the effect of one being on another, but conceives of individual beings not as entities but as emergent, entangled, mobile multiplicities.
6. A curious argument is mounted in Vehmas and Watson (2016) that normativity is a good thing through which humanist ideals are constituted and through which our best attitudes to

disability are developed. Our analysis of normativity does not take up this cozy uncritical relation with it.

7. In contrast to collaborative autoethnography, which moves from the collaborating individuals' accounts to an insight into some aspect of the social that is under investigation, collective biography works collaboratively on the memories from individual lives to shift them from being stories about individualized selves to stories about whichever aspect of the human condition is under investigation. As both methodologies are experimental and evolving, however, it is not useful to draw a sharp line between them.
8. This research strategy assumes that knowledge not only emerges out of data, but also out of the intra-action between the data and the researcher (Davies & Gannon, 2006). As a methodology, collective biography is in the first place inspired by the German scholar Frigga Haug's (1987) memory work. Memory work contains the writing and subsequent analysis of remembered stories that researchers collectively use to generate their own critique of theory. In the wake of Haug's memory strategies, collective biography uses memories and stories to explore the processes of subjectification (Davies et al., 2001). However, it differs from Haug's memory work in the sense that Haug (1987) is concerned in working from the point of view of the individualized subject and is interested in therapeutic outcomes, whereas collective biography is focused on the collective, intra-active constitution of subjectivities.
9. For a discussion of the power of wonder in collaborative writing, see Gale and Wyatt (2016), *Qualitative Inquiry*.
10. The technology and expertise that guided our filmmaking came from filmmaker Marieke Vandecasteele.
11. Emergent listening might begin with what is known, but it is open to creatively evolving into something new. Emergent listening opens up the possibility of new ways of knowing and new ways of being, both for who listen and those who are listened to (Davies, 2014).
12. The names used in this story are all pseudonyms.
13. A support worker is paid for by funds allocated by government to parents, so that parents can employ workers who work with the child to increase participation in society.

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**Leni Van Goidsenhoven** is a doctoral researcher of the Research Foundation-Flanders (FWO) at KU Leuven, connected to the research unit, Literary and Cultural Studies. Currently, she is preparing a PhD on "autism" and self-representation. She already published several articles and book chapters on this topic and she regularly gives workshops about "autism," self-expression, and creativity in Belgium and abroad. Her research interests cover life writing, disability studies, performance studies, outsider art, and the institutionalization of the self-help culture. As an assistant of Jan Hoet, she also created the exhibition Middle Gate Geel'13.

She studied art history and performance studies at Ghent University and literary studies at the University of Leuven.

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**Bronwyn Davies** is an independent scholar based in Sydney and a professorial fellow at the University of Melbourne. She is a writer, scholar, and teacher and has been a visiting professor in the last few years in the United States, Sweden, Denmark, Belgium, Finland, and the United Kingdom. She is well known for her work on gender, literacy, and pedagogy, and for her critique of neoliberalism. Her most recent books are *Listening to Children* and her first work of fiction for children, a new version of Pixie O’Harris’s classic story, *The Fairy Who Wouldn’t Fly*.